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I See You

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## **I See You**

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## I See You

I took a deep breath of surrender as I logged onto Zoom for the fourth straight hour of the day – my new COVID-19 work-from-home reality. But this hour would be different. This would be about listening to the narrative of my dear friend and colleague, Rachel (name changed to protect confidentiality), as she talked about providing tele-palliative care for oncology inpatients during the first pandemic surge in New York City.

As a researcher I had a clear aim: to objectively “understand her perceived self-efficacy in care delivered and her recommendations for future practice”.

As a palliative specialist myself, I wanted to provide a safe space for her to debrief and process her lived experiences.

And as a friend, I couldn't help but become tearful in solidarity with her as she opened up about the emotional distress of what it was like to feel both demoralized and powerless in the face of health system overwhelm.

New York City was a global hotspot for COVID-19 contagion and associated mortality in the spring and summer of 2020. As a nurse practitioner, Rachel had delivered most of her acute care consultations without ever laying eyes on her patients and families. She, and much of her palliative care team, all managed pain crises, spiritual emergencies, existential distress, ethical dilemmas, complex family dynamics, and the uncertainty of the dying process almost exclusively by phone over a ten-week period.

All these patients and their families – literally *unseen*. All these team members – also *unseen* by their patients. In many ways, it was a double-blinded recipe for cloistered suffering.

Rachel told me about the dissolution of the work-life boundary. During the COVID-19 surge, she worked most days from her living room, in the main area of her apartment, surrounded by comforts of the familiar and physically isolated from the many colleagues who so often provided the intermittent graces of perspective, levity, and hope. There was no 'leaving work at work' or using the walk home to release the day.

Her space had become her patient's. Her couch slowly evolved into a standing desk covered with their names... her personal phone's call history was filled with their numbers. Rachel's four walls stood like a stoic audience, unmoved by the heartbreak of the serious news she delivered and remaining silent alongside her as she listened to the cries of patients' loved ones. Her home – her refuge – had become invaded by the burden of COVID-19 coupled with the cumulative loss of cancer. It was an aggressive metastasis... consuming a bit more of her vitality each day.

She told me about being on the phone with the daughter and primary caregiver of a patient who was nearing the end of life. The daughter was crying – beside herself that 'something' had changed with her mother. Rachel responded with skill and empathy.

"I want you to look at your mother. Is she breathing?"

"No – she isn't."

The woman's mother had died. Rachel told the woman to ring the call bell and tried to provide some tele-compassion by cell phone – a seemingly insurmountable task in the moment.

Rachel updated the nurse, provided what guidance she could from her living room, and ended the call. And there she was in that apartment of hers... with only the

couch, the phone, the walls – stoic as ever, and the invasion of distress that had become a ‘normal’ part of a day’s work. She sat.

Grieving...

Alone...

*Unseen.*

During the interview, I provided the professional encouragement of any researcher. I expressed empathy. I acknowledged, normalized, and validated. I remained present and used the silence between us to support additional probes and prompts. But inside, my heart broke for her and for “us” – the broader “us” - as witnesses to this thing called cancer that had graduated to untenable in the face of a public health crisis.

Six hours later, I called her back – but this time, as her friend – to check on her and offer love to the hurting places she had exposed earlier... those places that were yearning to be *seen*.

Two years prior to commencing this study, I had stepped away from my own clinical practice. After more than a decade in critical care and palliative settings, working with patients across the serious illness continuum, I had become existentially traumatized (and I don’t use that phrase lightly). It took me months, possibly even years, to recognize my own suffering and realize that it was time to pause and metabolize some of the loss that I had witnessed so consistently.

Oh, the shame of saying, “I need a break!” “I need to step away!” “I can’t watch another person suffer!” Medicine rewards grit in the form of self-sacrifice. We laud colleagues who place the wellbeing of others before their own needs. But this is not

sustainable, and it isn't dignified and it's not human. I needed to admit that I was not a machine or a superhero. I was just me - with my own neuroses and lessons to learn. Here was Rachel, too – at full capacity and reaching the limits of her own radiant humanness. I knew this pain well. I knew it in my bones. And as we sat there – spirit to spirit and bone to bone – we saw each other.

There is an intense sadness emerging from deep within our palliative care community. Our colleagues – our friends – are sinking fast. Some are cultivating a healthy anger about the vaccine decliners and the workforce shortages and the overwhelmed COVID units. Others are just shutting down, losing their footing in the webs of despair we label burnout, moral injury, or post-traumatic stress. There are those finding comfort in groups of transparency, where the fatigue and sadness of the COVID context can be felt and integrated. But many are psychologically spent. Talking about it, reliving it, keeping the pain alive seems almost too much to bear. Many I speak with just want the invitation to feel acknowledged and *seen*.

In bereavement work, we recognize complicated grief as a complex and persistent state of mourning. There is an intensity to the sorrow and potential rumination over the deceased; there is excessive focus on the death accompanied by numbness, detachment, or bitterness about the loss. There may be an inability to trust others or enjoy life. Complicated grief may carry with it the shadows of depression, guilt, and shame but also feelings that life may not be worth living. I can't imagine a single one of our palliative nurses, physicians, social workers, chaplains, nutritionists, pharmacists, or any of our dear friends thinking that for even one moment their life is not worth living.

But it's happening.

Take a look around.

We are a palliative care community – a society - experiencing complicated grief. Our collective sadness and relationship to loss has become just that... complicated.

Just a few weeks ago, about ten months since that interview with Rachel, I sat with her on my New York City rooftop enjoying a summer night and a bowl of red cherries. I was in full friend mode and had shrugged off the researcher label before enjoying some fresh August air. Our metal chairs squeaked as we took turns leaning forward to share secrets and spit out cherry pits. Wine was conveniently handy and there was that type of stillness that taps you on the shoulder to let you know, “This is a special moment.”

I asked Rachel how she felt about “all of it” – the past year, the pandemic, work. She held her breath at first and was finally able to answer with tears. After a longer pause, she told me that the interview we had all those months ago remained the only chance she has had to speak openly and honestly with a colleague about the pain and grief that continues to haunt her all these months later. She has sought out therapy for the first time in her very long career and discovered a pressing need to focus on her mental health. Rachel is just like any one of us answering the call to care for patients with serious illness... treading precariously to stay afloat on a high tide of grief - the complicated kind.

It was 7pm on the rooftop. One year prior - at this time - there would have been applause, pots banging, horns blowing, and voices cheering with abandon for the health workers of Manhattan to celebrate, honor, and thank them. Now, there was a noticeable silence among the city dwellers.



No more applause. Just an expectation that Rachel and the so many like her get up and go to work the next day... unprocessed trauma and all.

I see you, Rachel. I have your back. Most important, you are not alone.

I see you, all. I do – I see you.

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